alzheimer's association

TESTIMONY OF

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Good afternoon, Chairman Craig and members of the committee. Thank you for inviting the Alzheimer's Association to testify about the opportunities and challenges of assistive technologies for persons with Alzheimer's disease.

The growing epidemic of Alzheimer's disease is generating catastrophic human and economic costs to American society and to societies around the world. The goal of the Alzheimer's Association, working in partnership with government and private industry, is to eradicate this disease. Through these combined efforts of the Association, National Institutes of Health, and the pharmaceutical industry, advances in medical treatment have surged forward in recent years. In the meantime, we must improve diagnosis, treatment and care; support family caregivers; address human resource challenges in the delivery of health care services; and improve care in facilities, at home, and in communities, whether rural, suburban or urban. We must do this in cost-effective ways that enhance quality of life for individuals, families and caregivers.

These are no small challenges, but technology provides enormous opportunities for addressing them. The Alzheimer's Association has assumed a leadership role by investing significant resources in exploring these technologies through the creation of a Technology Workgroup, by launching with Intel Corporation the Everyday Technologies for Alzheimer Care consortium, and by joining the Center for Aging Services Technologies commission sponsored by the American Association of Homes & Services for the Aging. In addition, the Alzheimer's Association recently announced that more than 150 local, state and national organizations representing more than 50 million Americans have come together to form the "Coalition of Hope" – the largest coalition ever organized to support increased funding for research to find new treatments to help those with Alzheimer's disease. We are pleased that the Senate Special Committee on Aging has called this hearing today and we look forward to working with the Committee and other government agencies to advance the technology and aging services agenda.

While much of the developmental work in technology is being carried out by private sector organizations, the Alzheimer's Association believes there is a definite role for the federal government. In addition to continued oversight, a key role is to bring stakeholders together in order to draw attention to the issues and give impetus to developmental efforts. A national commission on technology and aging, with special emphasis on those with cognitive impairments, should be created to focus public and private attention and resources on addressing these issues. A series of additional hearings should be convened to provide oversight on progress, to stimulate interest among various stakeholders, and to identify policy impediments to implementation of technological solutions.

Other roles for the federal government include supporting research on assistive technology in partnership with private industry and voluntary health agencies like the Alzheimer's Association. In addition, emphasis should be place on continuing and increasing federal funding for Alzheimer's disease research to maintain the momentum of advanced understanding of the causes and potential treatments of the disease while also seeking to find solutions for improving the care of those already diagnosed with the disease.

The Growing Alzheimer Epidemic

The challenges posed by Alzheimer's disease affect this country at a personal, an economic, and a societal level. An estimated 4.5 million Americans currently have Alzheimer's disease.[1] Increasing age is the greatest risk factor for Alzheimer's. One in ten individuals over age 65 and nearly half over 85 are affected.[2] The number of Americans with Alzheimer's will continue to grow as our population ages and life expectancy rates soar. By 2050, Alzheimer's could affect anywhere from 11.3 million to 16 million people.[3]

Caring for persons with Alzheimer's disease takes an enormous toll on the U.S. healthcare system. At any particular time, approximately 20 percent (1.1 million) of persons with Alzheimer's are in nursing homes and between five and ten percent (450,000 - 600,000) are in assisted living facilities.[4] By 2010, Medicare costs for beneficiaries with Alzheimer's are expected to increase nearly 55 percent, from $31.9 billion in 2000 to $49.3 billion and Medicaid expenditures on residential dementia care will increase 80 percent, from $18.2 billion to $33 billion.[5] Nearly half (49 percent) of Medicare beneficiaries who have Alzheimer's disease also receive Medicaid.[6] The average annual cost of Alzheimer care in a nursing home is $64,000.[7] Medicaid pays nearly half of the total nursing home bill and helps two out of three residents pay for their care. Alzheimer's disease costs American business $61 billion annually, $36.5 billion of which is caused by the lost productivity of employees who are caregivers.[8] Utilizing assistive technologies to prolong a person's ability to live independently, thus reducing the need for expensive institutional care, has the potential to save billions of dollars in Medicare and Medicaid spending, as well as family budgets.

Caring for persons with Alzheimer's also places a heavy burden on the families and friends of those with the disease. Alzheimer caregiving is intense, hard, and exhausting work. Seventy percent of people with Alzheimer's live at home, where family and friends provide the majority of their care.[9] Alzheimer caregivers devote more time to the day-to-day tasks of caring and they provide help with greater numbers of activities of daily living (including incontinence, one of the biggest challenges of caregiving). One in eight Alzheimer caregivers becomes ill or injured as a direct result of caregiving and one in three uses medications for problems related to caregiving.[10] Older caregivers are three times more likely to become clinically depressed than others in their

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[1] Hebert, LE; Scherr, PA; Bienias, JL; Bennett, DA; Evans, DA. "Alzheimer Disease in the U.S. Population: Prevalence Estimates Using the 2000 Census." *Archives of Neurology* August 2003; 60 (8): 1119 – 1122.

[2] Evans, DA; Funkenstein, HH; Albert, MS; et al. "Prevalence of Alzheimer's Disease in a Community Population of Older Persons: Higher than Previously Reported." *JAMA* 1989; 262(18): 2552 – 2556.

[3] Evans, *op cit*.

[4] Centers for Medicare & Medicaid Services, FY 2000 Medicare claims data for a 5% random sample of Medicare beneficiaries.

[5] Medicare and Medicaid Costs for People with Alzheimer's Disease. Washington, D.C.: April 2001: The Lewin Group.

[6] Health Care Financing Administration, Data from Current Beneficiary Survey. Presentation Materials from HCFA.

[7] P. Fox *et al.* (2001) "Estimating the Costs of Caring for People with Alzheimer's Disease in California: 2000-2040" *Journal of Public Health Policy* (I) (2001) 88-97

[8] Koppel, R. Alzheimer's Disease: The Costs to U.S. Businesses in 2002. Washington, D.C.: Alzheimer's Association; 2002.

[9] Losing a Million Minds: Confronting the Tragedy of Alzheimer's Disease and Other Dementias. U.S. Congress Office of Technology Assessment; U.S. Government Printing Office, 1987.

[10] S Tennestedt et at "*Depression among Caregivers of Impaired Elders"* New England Research Institute, Watertown, MA (1990).

age group [11]and one study found that elderly spouses strained by caregiving were 63 percent more likely to die during a four-year period than other spouses their age.[12] Assistive devices that allow individuals with cognitive impairments to complete activities of daily living with less dependence on their caregivers is one area in which technology may help alleviate some of the fatigue and "caregiver burnout" faced by loved ones of individuals with Alzheimer's disease.

The caregiving challenges presented by Alzheimer's disease extend to the long term care workforce as well. Today more than 1 million nursing assistants provide as much as 90 percent of hands-on care in nursing homes and other settings.[13] The Bureau of Labor Statistics estimates that by 2006, personal home and care aides are projected to be the fourth-fastest growing occupation, with a dramatic 84.7 percent growth rate expected.[14] Despite the growth in the industry and the increased demand for talented workers, there is a long term care workforce crisis. National long term care staff turnover rates are at an alarming 94 percent annually.[15] Numerous issues contribute to this crisis including insufficient staff, low wages, inadequate benefits, lack of dementia-specific training, little or no job recognition and few career advancement opportunities. Staffing shortages affect the overall quality of care to residents and contribute directly to staff turnover. One of the most important steps toward improving the quality of care is better training. Certified Nursing Assistants surveyed in a 1999 Iowa Caregiver's Association report indicated that their work was increasingly demanding and complex and that they needed more training and orientation. Respondents specifically mentioned the importance of Alzheimer's training and understanding behaviors related to dementia. With up to 16 million people expected to develop Alzheimer's disease by the middle of the 21st century, nearly all of whom will eventually require total care, a solution to the workforce crisis must be found immediately.[16] Technology that can be used to provide ongoing, interactive training for staff in long term care facilities is one part of the solution to the broader workforce problem.

Individuals living with Alzheimer's disease face challenges at all stages of the disease. Common symptoms at the beginning and moderate stages are impaired memory, judgment, and reasoning ability. As Alzheimer's progresses, individuals with the disease may lose the ability to manage their own health care, may not be able to follow medication instructions, and may need frequent cueing or reminders when completing routine tasks. All are likely at some point in the disease process to require 24-hour supervision and assistance. Individuals with Alzheimer's may also experience difficult or challenging behavior problems that lead to violent episodes, an issue explored by this committee in a hearing just last month. Several population-based studies have found that upwards of 90 percent of people with dementia develop one or more psychiatric and

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[11] Tennestedt, *op cit.*

[12] R Shultz et al "Caregiving as a Risk Factor for Mortality" *Journal of American Medicine* 282:23 (Dec 15, 1999).

[13] *Direct-Care Health Workers – The Unnecessary Crisis in Long Term Care*. Washington, DC: January 2001: Paraprofessional Healthcare Institute.

[14] U.S. Bureau of Labor Statistics. National Occupational Employment And Wage Estimates for 2000. Washington, DC.

[15] U.S. General Accounting Office. Testimony by William Scanlon, Director, Health Care Issues: Nursing Workforce: Recruitment and Retention of Nurses and Nurse Aides Is A Growing Concern. GAO-02-750T. U.S. General Accounting Office: Washington, DC.

[16] Evans, *op cit*.

related behavioral problems.[17] Wandering is another common and potentially life-threatening behavior associated with Alzheimer's disease. Studies report wandering in 4 to 26 percent of nursing home residents with dementia and in up to 59 percent of community-residing individuals suffering from the disease. Utilizing existing technology, such as electronic monitoring devices, may provide solutions to the everyday challenges faced by individuals with Alzheimer's disease.

The Potential of Technology

Technological innovations have enormous potential to address some of the challenges posed by Alzheimer's disease. Through our partnership with The Center for Aging Services Technologies (CAST), the Alzheimer's Association is working to identify how technology can improve Alzheimer care and services.

CAST has identified four areas where technology might improve aging services - providing ways to improve independence and allow people to remain independent longer (enabling); addressing the human resources and productivity issues of aging services providers (operational); improving the connections between individuals and their families and social support networks (connective); and dealing with geographic barriers to good care (telemedicine). These focus areas coincide with key priority areas for Alzheimer care.

An example of enabling technology that may help prolong independent living is a "Smart House" that includes features such as stoves with automatic cutoff devices and kitchen heat sensors to prevent fires. "Smart-Houses" may also include devices that cue and remind individuals with Alzheimer's disease to take medications or help them locate lost possessions. In addition, Artificial Intelligence is being tested to help individuals with Alzheimer's disease complete activities of daily living with less dependence on their caregivers.

Promoting safety is another major concern of the Alzheimer's Association. A wide variety of electronic tracking devices are currently available to monitor, track and locate individuals with Alzheimer's disease who wander. The Alzheimer's Association recently held a vendor conference and will soon be pilot testing electronic monitoring devices for possible widespread use.

Operational technology to address human resources and productivity issues includes Interactive Voice Response (IVR) systems that can be used to facilitate dementia screening, education and treatment referrals for staff at multiple sites. In addition, robotics and dynamic video can enhance access to interactive training and supervision for staff in long term care settings. Connective technology to improve the linkages between individuals, their families and social support networks includes IVR systems designed to assist family caregivers in managing persons with disruptive behaviors related to Alzheimer's disease. Other IVR systems are using voicemail networks to measure caregiver stress and provide access to care experts via telephone.

[17] Testimony of Constantine G. Lyketsos, MD, MHS, Professor of Psychiatry and Behavioral Sciences, Co-Director, Division of Geriatric Psychiatry and Neuropsychiatry, The Johns Hopkins University and Hospital Submitted to Committee on Aging, United States Senate Hearing on "Crime Without Criminals? Seniors, Dementia and the Aftermath", March 22, 2004, Washington, DC.

Telemedicine has the potential to reduce geographic barriers to good care. Telehealth and telemedicine technologies are being assessed for possible use in providing supervision (including monitoring sleep and eating patterns and medication compliance/accuracy) of individuals with Alzheimer's who live alone.

The Need for a Multi-Dimensional Approach

Developing, testing and measuring the viability and feasibility of various technologies to improve care and promote healthy aging requires collaboration among technology companies, researchers, service providers and advocacy organizations. Meeting the distinct needs of the aging population, particularly those with Alzheimer's disease, will require a complex, multi-dimensional approach. The Alzheimer's Association has already started down this road. In January 2001 we convened a Technology Work Group (TWG) to assess the impact of a broad spectrum of emerging technologies on the quality of care and health services for individuals with Alzheimer's disease. Not long after the Association formed the TWG, Intel Corporation launched its Proactive Health Research Project to explore ways in which "ubiquitous computing" could support the daily health and wellness of people in their homes and everyday lives.

Because of our shared interest in assistive technologies, Intel joined forces with the Alzheimer's Association to shape and implement a broader technology initiative. In July 2003, Intel Corporation and the Alzheimer's Association launched the Everyday Technologies for Alzheimer Care (ETAC) consortium. The goal of ETAC is to promote multidisciplinary, evidence-based research in computing, communications, and home health care technologies in Alzheimer's disease care settings. The ETAC initiative will fund research to identify and develop new models of Alzheimer care based up current and evolving technologies in these areas.

ETAC grew from the knowledge that as baby-boomers age: a) the number of people at risk for dementia is increasing dramatically; and b) current models and systems of care will not be adequate to accommodate increasing demands for individualized care. In recent years, while advances in treatments for brief symptomatic relief have surged forward, progress in improving services and technologies for routine care of people with prolonged disability and loss of independent functioning have lagged behind. Delaying and eventually preventing cognitive impairments could have far greater significance for the economics of health and well being than providing short-term, symptomatic relief.

ETAC will stimulate research crossing a variety of disciplines, including: 1) neuroscience, 2) emerging technologies in computing (e.g., communications, robotics, sensors, etc.), and 3) care needs of people with various types and levels of disability. ETAC will create a national forum for technology transfer by facilitating the exchange of ideas and collaborative research among experts from diverse disciplines, including: bioengineering, robotics, artificial intelligence, materials engineering, communications, systems design, software engineering, sensor/transducer networking, architecture, health services, nursing, biology, economics, business, caregiving, etc. This national alliance will promote research, development, and validation of user-friendly technologies as labor saving solutions to difficult and stressful problems of daily care.

Some of the practical outcomes expected by this program include improvements in:

- detecting and preparing for the onset of functional decline;
- delaying the onset of disabling symptoms;
- compensating for function impairments to maintain independence;
- providing support for caregivers to help alleviate stress and depression;
- postponing or preventing placement in residential care settings; and
- increasing accessibility to needed and appropriate healthcare services.

ETAC is an alliance harnessing new and existing technologies to meet the greatly expanding care needs of older Americans. The ETAC consortium is committed to enabling the development, testing, and marketing of assistive technologies to support the daily living needs of persons with cognitive impairment and their caregivers.

Public Policy Issues

There are a variety of public policy aspects, especially around reimbursement and regulatory issues, that may influence the broader development and adoption of assistive technologies for seniors and individuals with Alzheimer's disease. For example, alternative treatment models using telemedicine to help manage care for persons with Alzheimer's disease in rural areas might be very successful, but these models are not currently reimbursable, or reimbursement is very cumbersome. Determining how to measure the practical and care outcomes of using technology, conducting additional research to assess whether technology can reduce the cost of care or increase caregiver efficiency, and promoting more widespread use of existing technology in various care settings are just a few of the challenges faced by this burgeoning field. It will be necessary for government and private industry to examine all public policies, including possible Medicare and Medicaid reimbursement, to determine the impact on the development, adoption and use of technology.

Special Challenges for those with Alzheimer's and other Cognitive Impairments

Efforts to incorporate the use of technology more broadly in the care of persons with cognitive impairments such as Alzheimer's disease pose some unique challenges for caregivers in all settings. These challenges include:

- Adapting existing technologies so that they can be utilized by people with cognitive impairments
- Determining the applicability of existing technologies in various Alzheimer care settings
- Considering the ethical issues related to use of technology, such as obtaining consent, maintaining privacy rights and preserving decision-making autonomy for individuals with cognitive impairments
- Responding to cultural, language and ethnicity issues, both in how people will react to technology and to ensure technology is diffused into communities in ways that are culturally appropriate
- Developing models that integrate human aspects with technology to deliver high quality care with greater efficiency.

All of these issues can be addressed, and while they address issues specific to people with cognitive impairments, they are important to everyone who will be using or be affected by technology in care settings. The Alzheimer's Association Ethics Advisory Panel is one group that could begin to address these issues now.

Recommendations for Government

As was acknowledged earlier, much of the developmental work in technology is being carried out by private sector organizations the Alzheimer's Association believes the federal government can play a role in this area by:

- Creating a national commission on technology and aging, with a special emphasis on those with cognitive impairments, to focus public and private attention and resources on addressing these issues.
- Supporting research on assistive technology in partnership with private industry and voluntary health agencies like the Alzheimer's Association.
- Convening a series of additional hearings to provide oversight on progress, to stimulate interest among various stakeholders and to identify policy impediments to implementation of technological solutions.
- Continuing and increasing federal funding for Alzheimer's disease research to maintain the momentum of advanced understanding of the causes and potential treatments of the disease while also seeking to find solutions for improving the care of those already diagnosed with the disease.

Conclusion

Thank you, Mr. Chairman, for calling this important hearing. We have entered a new era in the fight against Alzheimer's disease. Over the last twenty years we have gone from hopeless to hopeful and are at the point where the goal of a world without Alzheimer's disease is within reach. Working collaboratively, the federal government, the scientific community, the Alzheimer's Association and the pharmaceutical industry have made tremendous progress in the prevention, diagnosis and treatment of Alzheimer's disease. Even with the progress that has been made, we still face many challenges, especially in delivering health care services and improving care for individuals with Alzheimer's disease in facilities, at home and in communities. These are big challenges but technology provides enormous opportunities for addressing them. The Alzheimer's Association has assumed a leadership role by investing significant resources in exploring these technologies through the creation of a Technology Workgroup, by launching with Intel Corporation the Everyday Technologies for Alzheimer Care consortium, and by joining the Center for Aging Services Technologies commission sponsored by the American Association of Homes & Services for the Aging. While much of the developmental work in technology is being carried out by private sector organizations, it is essential that the federal government intervene to enable both sectors to focus more attention and resources on this promising area. We are committed to working with you and all of our partner organizations to shape a future in which technology will improve the lives of people with chronic conditions like Alzheimer's disease, as well as the lives of their caregivers and families.